Linkage of Hospital Episode Statistics (HES) Data to Office for National Statistics (ONS) Mortality Records

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Executive Summary

This report describes work undertaken to evaluate the extent to which deaths recorded within the Hospital Episode Statistics (HES) system can be regarded as providing a reliable surrogate for 30-day mortality in the context of paediatric cardiac surgery during the period 1991 to 1995. This is important because evidence submitted to the Inquiry has suggested that HES data could substantially under-estimate 30-day mortality. If this were so, and if there was substantial variation from centre to centre in the reliability of the mortality data, then this could introduce an important bias into the comparative statistical analyses which have been presented to the Inquiry.

The reliability of the reporting of mortality within HES was assessed by linking the HES records to national mortality records collected by the Office for National Statistics (ONS). The methodology was based on the system which has been used for many years in Scotland to link the Scottish equivalent of the HES data (the Scottish Morbidity Records) to national mortality records.

The linkage exercise was highly successful. The results indicate that HES reliably records in-hospital deaths, but that a substantial number of deaths occur after discharge from hospital but within 30 days of the primary surgical procedure. As would be expected, the majority of these post-discharge deaths are not recorded within HES. Overall it is estimated that 8.4% of 30-day deaths are not recorded within HES, with this figure ranging amongst the Inquiry centres from 3% to 19%. The corresponding estimate in the subgroup of children aged under one year and undergoing open surgical procedures is 5.2% with a range from 0% to 12%. Missed links between the HES and ONS records mean that these figures will under-estimate the true proportion of 30-day deaths which are not recorded within HES.

The implications of these findings for the interpretation of the statistical results already presented to the Inquiry will be discussed in a document being prepared by the Inquiry's statistical analysts, under the leadership of Dr David Spiegelhalter.

The exercise illustrates the feasibility of linking HES data to national mortality records. We believe that this should become routine practice within the Health Service in England and Wales, just as it has become routine practice within the NHS in Scotland. This requires difficult issues relating to data privacy to be addressed.

List of Abbreviations

HES	Hospital Episode Statistics
ISD	Information & Statistics Division (of the NHS in Scotland)
NHS	National Health Service
ONS	Office for National Statistics
OPCS	Office of Population Censuses and Surveys
UKCSR	United Kingdom Cardiac Surgical Register

1. Introduction

1.1 Background

1.1.1 A major point to arise from the statistical evidence presented to the Bristol Royal Infirmary Inquiry on 3rd November 1999 is that there are no procedures in place to ensure systematic follow-up of patients following surgery to determine and record their vital status (1). In particular, the data on 30-day mortality which were the basis for the majority of the formal analyses could miss deaths occurring between discharge and 30 days. There is potential for the reliability of the mortality data to vary from centre to centre, which could generate a bias in the comparative analyses. These issues were further highlighted in a review commissioned by the Inquiry of data collection practices for the national register compiled by the Society of Cardiothoracic Surgeons of Great Britain and Ireland (The United Kingdom Cardiac Surgical Register, UKCSR) (2).

1.1.2 The UKCSR data are compiled at an aggregate level, but the Hospital Episode Statistics (HES) database, analysed by Dr Aylin and colleagues (3), records data on individual children. Given that there is a legal requirement to register all deaths, there is clearly potential to attempt to evaluate the reliability of the reporting of death through the HES system by linking relevant HES records to the central Office for National Statistics (ONS) mortality records.

1.1.3 There is extensive experience within the National Health Service in Scotland of record linkage using the Scottish equivalent of the HES data (Scottish Morbidity Records) and the corresponding national mortality records (4). This has been used, for example, as the basis for audit reports (5), epidemiological studies (6), and as a validation tool in randomised clinical trials (7). To our knowledge, there have been no such comprehensive attempts to link HES data to ONS mortality records.

1.2 ONS Registration of Deaths

1.2.1 The Office for National Statistics (ONS) was formed on 1st April 1996, bringing together the Office of Population Censuses and Surveys (OPCS) and the Central Statistical Office. The procedures for registering deaths, including the procedures in place during the Inquiry period which pre-dates the formation of the ONS, are described in 'Mortality statistics: Childhood, infant and perinatal' (8). When a death occurs, the attending doctor is required to complete a certificate of cause of death to be taken to the local registrar of births and deaths. The person delivering the doctor's certificate to the registrar, known as the informant, is often a relative of the deceased. The particulars to be registered concerning a death are set out in the Births and Deaths Registration Act 1953, and include the date and place of death, and the deceased's sex, date of birth and usual place of residence. Deaths of persons whose usual residence is outside England and Wales are included in the registration system if the death takes place in England or Wales. Extensive checks are performed to ensure the completeness of coverage of the registration of deaths (8).

1.2.2 The data relating to cause of death are less robust. 'A variety of studies have looked at the quality of information on death certificates, in particular the details on cause of death. With many thousands of doctors writing certificates, and with the variation in their training, habits and knowledge, the quality will inevitably be inconsistent' (8).

1.2.3 The procedures for managing the registration data changed substantially in 1993, with the redevelopment of OPCS collection and processing systems (9). Changes included the computerisation of registration, with most local offices entering data on microcomputers and supplying data to ONS on floppy disk. Procedures were also introduced to automate the coding of cause of death.

2. Aims of the Exercise

2.1 The main aims were twofold:

- to evaluate the reliability with which HES captures in-hospital mortality following paediatric cardiac surgery;

- to estimate the number of deaths occurring after discharge from hospital but still within 30 days of the primary surgical procedure.

2.2 Differences between centres, and according to the age of the child and the type of surgical procedure were to be explored. Discrepancies between discharge method, discharge destination, date of discharge and date of death were also to be explored.

2.3 The linked HES/ONS data set also provided the opportunity to investigate concerns raised by Lawrence and Murray (2) over the completeness of the reporting of mortality in the UKCSR. This was not an initial aim of the linkage exercise, but this report presents data relating to this issue.

3. Scope of the Exercise

3.1 The analysis was based on the spells of linked episodes identified in the analyses reported previously by Aylin et al (3). Data were provided for Epoch 3, 1st April 1991 to 31st March 1995.

3.2 Extracts of all ONS mortality records for England and Wales with dates of birth from 1st January 1975 to 31st December 1995 and with dates of death from 1st January 1991 onwards were provided. This covers any children who were operated upon during Epoch 3, assuming that there are no errors in dates of birth or dates of death in the ONS data.

3.3 Data linkage was attempted using the patient's date of birth, sex and postcode.

4. Methods

4.1 Data Requested

4.1.1 The mortality records were requested directly from the Office for National Statistics, and were supplied once an appropriate confidentiality declaration had been signed. The HES data were supplied through the Imperial College School of Medicine, and were supplied in the format of spells of linked episodes, as described in the report of Aylin et al (3). Release of these data required a formal application to the Department of Health, and was only possible after detailed scrutiny by the NHS Security and Confidentiality Advisory Group and subsequent discussion with the Department of Health. The application process was facilitated by the Inquiry Secretariat.

4.1.2 The time windows, etc, are specified above. The following fields were requested:

HES:

Provider (i.e. hospital)
Date of Birth
Sex
Postcode
Date of Admission
Date of Primary Procedure
OPCS 4 code for primary procedure
Consensus Group (see Aylin at al (3))
Open/Closed (see Aylin at al (3))
Date of Discharge
Mode of Discharge
Discharge Destination
Date of Death

ONS:

Date of Birth
Sex
Postcode
Date of Death
Cause of Death

4.2 Data Checking

4.2.1 Extensive checks were run to assess the quality of the data. In general any problems identified were documented but the data were not edited. The one exception was with the postcode data, where the number of spaces between the two parts of the postcode was not consistent. The postcodes were edited to a consistent format to allow record linkage on the basis of the postcode.

4.3 Data Linkage

4.3.1 The data linkage performed by the Information & Statistics Division of the National Health Service in Scotland (ISD) was based on date of birth, sex and postcode, but also took account of HES dates of discharge which corresponded closely to ONS dates of death. The analysis used the technique of probability matching (10). Probability matching translates the level of agreement and disagreement between each item of identifying information on two records – for example both records might have a postcode district of TW12 or there might be a discrepancy of exactly one year in the date of birth – into a mathematical score or probability weight, which can be aggregated across all items to produce a measure of the likelihood that the two records belong to the same individual. In the experience of ISD the method of probability matching is estimated to be 13-14% more accurate than 'exact matching'.

4.3.2 Postcode weights were derived from the NHS Postcode Directory (standard full version) supplied by ONS. Weights were calculated for area (2 characters), area and district (4 characters), area, district and sector (5 characters), area, district, sector and first character of unit (6 characters) and full postcode (7 characters). 'ZZ' postcodes were weighted only at the area level (2 characters).

4.3.3 It had originally been the intention to augment the linkage exercise for the Bristol data alone by using a variety of the local sources describing surgical activity and outcome there during the Inquiry period. This might have helped to resolve problems where, for example, there was a death reported by HES but with no obviously matching record from ONS. However, the results of the ISD linkage were so successful that it was not thought that such augmentation would 'add value' to the analysis.

4.4 Statistical Methods

4.4.1 The presentation of the results is purely descriptive.

5. Results

5.1 Data Received

5.1.1 HES: A file containing 11,952 records was received from Imperial College School of Medicine. Each record corresponded to a spell of linked episodes, as described in Aylin et al (3). The admission dates covered the interval 1st April 1991 to 31st March 1995, 'Epoch 3' of the Inquiry period. Many children had multiple spells over this period, and the 11,952 spells related to a total of 11,022 children. The fields included in the extracted file are set out in Table 1.

5.1.2 ONS: The mortality data were supplied by the Office for National Statistics. A total of 49,679 death records were supplied in three separate files, the files reflecting changes over time in the way in which data on cause of death were recorded. The structure of the three files is set out in Tables 2a to 2c.

5.1.3 File AL359192 contained 14,111 records for deaths recorded in 1991 and 1992 (Table 2a). File AL359399 contained 27,243 records for deaths in children aged over 28 days recorded from 1993 to 1999 (Table 2b). File AL035NEO contained 8,325 records for neo-natal deaths registered from 1993 to 1999 (Table 2c).

5.2 Data Quality

5.2.1 HES

5.2.1.1 Table 3 summarises the results of a detailed check of the completeness of the HES data and its compliance with valid codes and ranges. From the point of view of the linkage exercise, the main causes of concern were problems with the postcode data and missing or invalid dates of surgery and discharge. 777 records had postcodes starting with 'ZZ' which appear to have been used for patients from overseas, and 231 records contained invalid postcodes. 411 records had no date of discharge recorded, and a number of date fields included what appear to be 'dummy' dates of 31st December 1899 and 15th October 1982.

5.2.1.2 As well as the range and completeness checks, a number of logical checks were run to examine consistency between fields. It was found that 17 records matched another record on all variables other than 'SPELL', and 26 records matched another record on patient number, date of birth and date of admission.

5.2.1.3 There were 131 records where the dates of birth, admission, primary procedure and discharge were not in a logical order (e.g. there were 99 records where the date of the primary procedure is before the date of birth). A large proportion of these inconsistencies arose from the use of 'dummy' dates of 31st December 1899 and 15th October 1982.

5.2.1.4 There were gross inconsistencies between method of discharge, discharge destination and the derived outcome variable. It was subsequently clarified that the derived outcome variable was based on information from each episode in a spell, whereas the method of discharge and discharge destination only related to one of the episodes. It would be useful to go back to the original data on episodes and explore the inconsistencies between method of discharge and discharge destination. This point is raised again later in the Results section. The derived outcome variable has been used in all analyses presented in this report.

5.2.2 ONS

5.2.2.1 Over the three files, there were 645 records with no postcode recorded, and 272 records with a 'ZZ' postcode. Fifteen records had a Scottish postcode. 96 records have '00' entered for day of birth and 25 have this blank. 79 records had '00' entered for month of birth and 20 had this blank. 39 records had '00' entered for day of death and 38 records had '00' entered for month of death.

5.2.2.2 In addition to the above range and completeness checks, a series of logical checks identified the following problems with the ONS records. For file AL359192 there were 229 duplications, with 112 records being present two or more times (although occasionally 'other main causes of death' differed). All dates of birth and dates of death were in a consistent order. For file AL359399 there were 32 duplications, with 16 records being present twice. All dates of birth and dates of death were in a consistent order. For file AL035NEO there were 216 duplications, with 104 records being present two or more times (although occasionally information on cause of death differed). All dates of birth and dates of death were in a consistent order.

5.3 ISD Linkage

5.3.1 The original file of HES records was reduced to one record per individual by taking the last spell for each child. This left 11,022 records. The ISD linkage identified 1,150 matching ONS death records. Of these, 978 (85%) were perfect matches on date of birth, sex and full postcode. A further 123 cases were not linked to an ONS mortality record but were coded as dead according to the derived outcome field on the HES records.

5.3.2 These 1,273 (1,150 + 123) deaths identified by the ISD linkage and/or the HES records are summarised in Table 4. This gives the total number of deaths at each of the twelve Inquiry centres, together with the 57 deaths where the HES provider code did not correspond to any of the twelve Inquiry centres. Of the 1,273 deaths, 450 were not recorded as such by HES. A large majority of these 'missed' deaths occurred well beyond the end of the relevant HES spell.

5.3.3 The deaths were split further according to whether they were within 30 days of the primary surgical procedure, and by whether they occurred in-hospital or post-discharge. It was not possible to classify 28 deaths within 30 days of surgery and 11 deaths beyond 30 days as either in-hospital or post-discharge, because the data on date of discharge and date of death were incomplete or inconsistent.

5.3.4 There was insufficient time to check all of these 39 cases against the HES data for the original HES episodes, but three cases were investigated in detail to ensure that there had not been a problem with the extraction of the summarised data on spells, nor any problems with the interpretation of the extracted HES data. For these three cases, the problems existed at the level of the original episodes. For example, in one case an entire episode record was duplicated, but with the date of admission exactly one year after the date for the first record. The patient died shortly after the first admission date, but since we used the last spell for each patient we had selected the erroneous duplicate record with the date of admission one year after the date of death.

5.3.5 Of the 795 deaths coded clearly as being in-hospital, HES captured 789 (99.2%). Sixty-four deaths were identified as occurring post-discharge but within 30 days of the primary surgical procedure, and HES did not capture 49 (77%) of these deaths.

5.3.6 Tables 5 to 10 give these same data split by the type of surgery (open versus closed) and the age of the child (0 to 90 days; 91 to 365 days; over 365 days).

5.3.7 Table 11 summarises the number of deaths occurring within 30 days of the primary surgical procedure which were not captured by HES, both overall and also for the subgroup of children aged under one year undergoing open surgery. Overall HES did not capture 68 of the 806 30-day deaths (8.4%), with the rate for individual centres ranging from 3% to 19%. The corresponding figures for children aged under one year undergoing open surgery were 21 missed 30-day deaths out of 407 (5.2%), with individual centre rates ranging from 0% to 12%. The data from Bristol do not stand out as being any more or any less reliable as those from the other centres.

5.3.8 The derived outcome variable for the 68 missed 30-day deaths was coded as follows: usual place of residence (n=28); temporary residence (n=1); HES provider (n=23); non-NHS hospital (n=3); unknown (n=13). For at least the 23 cases discharged to another HES provider it is conceivable that the deaths are recorded within the HES system, but that they were not identified when the HES episodes were linked to form spells for analysis.

5.4 Manual Linkage

5.4.1 The 123 cases where the derived HES outcome variable indicated death but where the ISD linkage did not identify a corresponding ONS death record were reviewed in detail. A substantial proportion came from the London hospitals, and the non-linkage was related to inconsistent usage of ‘ZZ’ postcodes between HES and ONS. It was possible manually to identify a well-matched ONS record for all but 16 of the 123 cases.

5.4.2 Further attempts were made to identify links missed in the ISD analysis. There are 34 cases with perfect postcode matches and very close date of birth matches, but where the date of death on the ONS record is before the date of discharge. These look very much as if the ONS dates are in error and that they are further 'missed' HES deaths. However, only ten relate to open procedures, and only five to open procedures in children aged under one year. It is obviously unclear whether they are within 30 days of surgery.

5.4.3 There are a further 14 cases with very close postcode and date of birth matches, which look like further 'missed' HES deaths. However, only two are 30 day deaths, one following an open procedure in a child aged over one year and one following a closed procedure in a child aged under one year.

5.5 Comparison with UKCSR Data

5.5.1 There is strong evidence that the 806 30-day deaths identified above did indeed occur in children in the relevant units. Other deaths might well have been missed, but these figures provide a lower limit for the number of 30-day deaths occurring over this period. Lawrence and Murray (2) raise serious concerns that the UKCSR data might under-report mortality, and if any UKCSR figures were below the lower limit provided by the linked HES deaths then this would provide very strong evidence that the UKCSR data do indeed under-report mortality.

5.5.2 Table 12 shows comparative annual numbers of deaths for HES/ONS and the UKCSR. The data for the UKCSR correspond to the calendar year 1992 and the financial years 1993/94 and 1994/95, and the HES data have been matched accordingly. There are no clear patterns seen in all centres over all years, but the UKCSR deaths are under-reported relative to the HES/ONS lower bound in Bristol for 1992, Leicester for 1993/94, Leeds for 1992 (the only year for which data are available), Oxford for all three years, Liverpool for 1994/95, Newcastle for all three years, Birmingham for 1993/94, and for the Brompton in 1993/94 and 1994/95.

6. Discussion

6.1 This exercise has shown very clearly that HES is extremely effective in capturing in-hospital deaths following paediatric cardiac surgery. Only six of the 795 deaths clearly coded as being in-hospital were missed by HES (0.8%).

6.2 It is equally apparent that a substantial number of deaths occur after discharge from hospital but within 30 days of the primary surgical procedure. As would be expected, HES does not capture the majority of these post-discharge 30-day deaths.

6.3 Overall, based on the ISD linkage, it appears that 8.4% of 30-day deaths are 'missed' by HES, with a range between centres of 3% to 19%. The corresponding rate for missed 30-day deaths following open procedures in children aged under one year is 5.2% with a range of 0% to 12%. The reason why the majority of these 'missed' deaths do not appear in the HES system is that they occur after the patient has been discharged from hospital, but still within 30 days of the primary surgical procedure. These figures will under-estimate the true proportion of missed deaths, since not every HES record for which there is a corresponding ONS death record will have been linked to the death record in the ISD linkage exercise. Indeed the additional manual linkage step identified a number of such matching HES and ONS records which had not been linked in the ISD exercise.

6.4 It is impossible using the available information to give a reliable estimate of the number of missed links, although the fact that our manual linkage did identify some additional matches suggests that the number is not negligible. To explore this issue thoroughly would require a far more extensive exercise which started with a sample of child deaths recorded by ONS and tried to identify the circumstances of the deaths, in particular whether they occurred following cardiac surgery. (See 6.6 below).

6.5 The impact of these findings on the interpretation of the statistical analyses already presented to the Inquiry will be discussed in an overview document to be prepared by Dr David Spiegelhalter. There will be input to this document by all the Inquiry analysts, namely Dr Paul Aylin, Professor Stephen Evans and Professor Gordon Murray.

6.6 This analysis only considers one aspect of the quality of the HES data. It explicitly does not look at the question of the coverage of the data, i.e. are there children undergoing cardiac surgery who do not appear in the system at all, or who were not identified because of errors in the recording of their date of birth or errors in the coding of their surgical procedure(s)? In his comments to the Inquiry, Mr Stark implies that this might be a substantial problem (11). If it were the case that cause of death was coded precisely and specifically on death certificates then it would have been possible to examine the question of the coverage of the HES records by working back from the ONS records of children who had died following cardiac surgery. However, because of the lack of specificity in the coding of cause of death, and because of time constraints, this approach was not pursued.

6.7 Incompleteness and inconsistencies within the HES records hampered the linkage exercise. It is not clear to what extent these problems reflect the underlying data on HES episodes as opposed to problems in linking the individual HES episodes into spells. In retrospect it would have been better to perform this exercise starting with data at the level of episodes and using probability matching to link the episodes into spells, although this would have been difficult to achieve within the time available.

6.8 Although the proportion of HES records containing clear inconsistencies was low, we believe that the very presence of such obvious errors contributes to the view widely prevalent amongst paediatric cardiac surgeons that the HES data are unreliable and not to be trusted (2). If such data are to gain credibility with clinicians then much greater attention needs to be paid to quality control, and resources need to be identified to ensure that quality can be 'built in'. The quality control procedures which are currently in place have been described to the Inquiry by Mr Richard Willmer (12).

6.9 One aspect of such quality control is linkage to national mortality records. This has been undertaken successfully and to great effect in Scotland since the 1970's (5,6,7). The current exercise shows that the experience and methodologies developed within ISD can be applied to HES/ONS data. If patients' names were available to contribute to the linkage process then the results would be substantially more robust.

6.10 Record linkage raises difficult issues relating to privacy and confidentiality. Almost by definition in record linkage one is using data for a purpose other than the purpose for which they were originally collected. This contravenes the principles of the 1998 Data Protection Act which has just come into force. Through the best of intentions, concerns for privacy risk strangling a methodology which is an enormously powerful tool both in the context of clinical governance and also in epidemiological research.

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Table 1: Data fields contained in the extracted HES file supplied by Imperial College School of Medicine.

PATIENT	
SPELL	
DOB	Date of birth
SEX	
PROCODE	Provider code (i.e. hospital)
POSTCODE	
ADMIDATE	Admission date
DISDATE	Discharge date
DISDEST	Discharge destination
DISMETH	Discharge method
OUTCOME	Derived from DISDEST and DISMETH
PRIMPROC	Primary procedure (OPCS4 coding)
PRIMOP	Inquiry consensus group for primary procedure
PRIMDATE	Date of primary procedure
PRIMTH	Coded 1 if outcome of spell unknown
PRIMDTH	Coded 1 for death
OPEN	Open/closed classification
OPENDATE	Date of open/closed
OPTR	Coded 1 if outcome of spell unknown
OPDTH	Coded 1 for death

Table 2a: Data fields for file AL359192 supplied by the Office for National Statistics giving death records for 1991 and 1992.

PCDR	Postcode of usual residence
SEX	
DOD	Date of death
DOB	Date of birth
NEOIND	Indicator for neo-natal death (i.e. death under 28 days)
FICODUND	Underlying cause of death (only for non neo-natal deaths)
FICODSEC	Secondary cause of death (only for non neo-natal deathjs)
ORGMCC	Original main condition –child (only for neo-natal deaths)
ORGMCM	Original main condition – mother (only for neo-natal deaths)
FMCC001-003	Up to 3 final main conditions – child (only for neo-natal deaths)
FMCM001-003	Up to 3 final main conditions – mother (only for neo-natal deaths)
OMCC001-008	Up to 8 other conditions – child (only for neo-natal deaths)
OMCM001-008	Up to 8 other conditions – mother (only for neo-natal deaths)

Table 2b: Data fields for file AL359399 supplied by the Office for National Statistics giving death records from 1993 to 1999 of children aged over 28 days.

PCDR	Postcode of usual residence
SEX	
FICODUND	Underlying cause of death
FICODSEC	Secondary cause of death
CESTRSS	Code for place of death
DOD	Date of death
DOB	Date of birth
FIMEN001-008	Up to 8 ‘mention fields’ of external or secondary causes of death

Table 2c: Data fields for file AL035NEO supplied by the Office for National Statistics giving death records from 1993 to 1999 of children aged under 28 days.

PCDR	Postcode of usual residence
SEX	
CESTRSS	Code for place of death
DOD	Date of death
DOB	Date of birth
FIMEN1-8	Up to 8 ‘mention fields’ for causes of death

Table 3: Summary of the results of completeness checks and range checks performed on the HES data.

PATIENT	There were 10,179 patients with exactly one spell, and 843 with 2 or more spells. The 11,952 spells related to a total of 11,022 patients.
DOB	There were no missing data in this field, and the dates ranged from 14th July 1975 to 31st March 1995
SEX	There were no missing data in this field, but 24 records had invalid codes.
PROCODE	There were no missing data in this field. All records contained codes which were in a valid format, but not all of the codes were included in the files of decodes which accompanied the data file.
POSTCODE	There were no missing data in this field. 777 records had a postcode starting 'ZZ', which appears to have been used for patients from overseas. 231 postcodes (including 25 'ZZ' codes) were not formatted as valid postcodes.
ADMIDATE	There were no missing data in this field, and the dates of admission ranged from 1st April 1991 to 31st March 1995.
DISDATE	411 records had no date of discharge recorded, and a further 27 records had an inappropriate date of 15th October 1982.
DISDEST	3000 records had codes which were not specified in the coding key ('-' and '&').
DISMETH	9 records had a code not specified in the coding key ('&').
OUTCOME	There were no missing data for this field.
PRIMPROC	2510 records were blank.
PRIMOP	2510 records were blank.
PRIMDATE	2891 records were blank. 13 records had the inappropriate date of 31st December 1899 and 90 records had the inappropriate date of 15th October 1982. Other dates ranged from 1st April 1991 to 25th September 1995.
OPEN	309 records were blank
OPENDATE	316 records were blank. 18 records had the inappropriate date of 31st December 1899 and 108 records had the inappropriate date of 15th October 1982. Other dates ranged from 1st April 1991 to 25th September 1995.

Table 4: Summary of all Deaths Identified by ISD Linkage and/or Reported in HES

The table entries are : ***Number of deaths (Number not recorded in HES)***

			Deaths within 30 days of Procedure			Deaths beyond 30 days of Procedure		
Inquiry Number	**Unit**	**Total Deaths**	**In-Hospital**	**Post-Discharge**	**?***	**In-Hospital**	**Post-Discharge**	**?***
1	Bristol	109 (34)	63 (0)	5 (1)	6 (2)	4 (0)	28 (28)	3 (3)
2	Leicester	55 (17)	37 (0)	4 (3)	0 (0)	0 (0)	14 (14)	0 (0)
3	Leeds	123 (63)	53 (1)	13 (12)	1 (0)	6 (0)	50 (50)	0 (0)
4	Oxford	68 (25)	35 (2)	3 (3)	2 (1)	8 (0)	19 (19)	1 (0)
5	Guys	57 (10)	38 (0)	2 (2)	2 (0)	6 (0)	9 (8)	0 (0)
6	Liverpool	146 (50)	87 (1)	3 (2)	1 (0)	8 (0)	47 (47)	0 (0)
7	Southampton	52 (17)	31 (0)	1 (1)	0 (0)	3 (0)	17 (16)	0 (0)
8	GOS	161 (52)	92 (0)	5 (3)	11 (9)	13 (0)	34 (34)	6 (6)
9	Newcastle	82 (31)	47 (0)	6 (6)	1 (0)	3 (0)	25 (25)	0 (0)
10	Harefield	93 (17)	68 (0)	5 (2)	0 (0)	5 (0)	15 (15)	0 (0)
11	Birmingham	147 (56)	81 (2)	7 (6)	3 (0)	8 (0)	48 (48)	0 (0)
12	Brompton	123 (55)	62 (0)	9 (7)	1 (1)	4 (0)	47 (47)	0 (0)
	Elsewhere	57 (23)	20 (0)	1 (1)	0 (0)	13 (0)	22 (22)	1 (0)
	Total	**1273 (450)**	**714 (6)**	**64 (49)**	**28 (13)**	**81 (0)**	**375 (373)**	**11 (9)**

?* - Dates missing or inconsistent

Table 5: Summary of Deaths Identified by ISD Linkage and/or Reported in HES

Closed Procedures in Children Aged 0 to 90 Days

The table entries are : ***Number of deaths (Number not recorded in HES)***

			Deaths within 30 days of Procedure			**Deaths beyond 30 days of Procedure**		
Inquiry Number	**Unit**	**Total Deaths**	**In-Hospital**	**Post-Discharge**	**?***	**In-Hospital**	**Post-Discharge**	**?***
1	Bristol	16 (10)	5 (0)	1 (1)	0 (0)	1 (0)	9 (9)	0 (0)
2	Leicester	9 (3)	6 (0)	1 (1)	0 (0)	0 (0)	2 (2)	0 (0)
3	Leeds	36 (29)	7 (0)	6 (6)	0 (0)	0 (0)	23 (23)	0 (0)
4	Oxford	19 (11)	4 (0)	3 (3)	1 (1)	4 (0)	7 (7)	0 (0)
5	Guys	7 (3)	4 (0)	0 (0)	0 (0)	0 (0)	3 (3)	0 (0)
6	Liverpool	29 (12)	15 (0)	0 (0)	0 (0)	2 (0)	12 (12)	0 (0)
7	Southampton	5 (2)	2 (0)	1 (1)	0 (0)	1 (0)	1 (1)	0 (0)
8	GOS	20 (7)	8 (0)	0 (0)	1 (1)	5 (0)	6 (6)	0 (0)
9	Newcastle	22 (18)	4 (0)	6 (6)	0 (0)	0 (0)	12 (12)	0 (0)
10	Harefield	5 (2)	3 (0)	0 (0)	0 (0)	0 (0)	2 (2)	0 (0)
11	Birmingham	30 (20)	10 (1)	4 (4)	0 (0)	1 (0)	15 (15)	0 (0)
12	Brompton	25 (24)	1 (0)	3 (3)	1 (1)	0 (0)	20 (20)	0 (0)
	Elsewhere	30 (7)	11 (0)	0 (0)	0 (0)	11 (0)	7 (7)	1 (0)
	Total	**253 (148)**	**80 (1)**	**25 (25)**	**3 (3)**	**25 (0)**	**119 (119)**	**1 (0)**

?* - Dates missing or inconsistent

Table 6: Summary of Deaths Identified by ISD Linkage and/or Reported in HES

Closed Procedures in Children Aged 91 to 365 Days

The table entries are : ***Number of deaths (Number not recorded in HES)***

			Deaths within 30 days of Procedure			**Deaths beyond 30 days of Procedure**		
Inquiry Number	**Unit**	**Total Deaths**	**In-Hospital**	**Post-Discharge**	**?***	**In-Hospital**	**Post-Discharge**	**?***
1	Bristol	6 (4)	2 (0)	0 (0)	0 (0)	0 (0)	4 (4)	0 (0)
2	Leicester	6 (5)	0 (0)	2 (1)	0 (0)	0 (0)	4 (4)	0 (0)
3	Leeds	7 (5)	3 (1)	1 (1)	0 (0)	0 (0)	3 (3)	0 (0)
4	Oxford	3 (2)	0 (0)	0 (0)	0 (0)	0 (0)	2 (2)	1 (0)
5	Guys	2 (1)	1 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)
6	Liverpool	4 (2)	2 (0)	0 (0)	0 (0)	0 (0)	2 (2)	0 (0)
7	Southampton	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)
8	GOS	4 (1)	3 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)
9	Newcastle	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
10	Harefield	2 (0)	2 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
11	Birmingham	3 (1)	2 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)
12	Brompton	10 (6)	4 (0)	2 (2)	0 (0)	0 (0)	4 (4)	0 (0)
	Elsewhere	6 (5)	1 (0)	1 (1)	0 (0)	0 (0)	4 (4)	0 (0)
	Total	**54 (33)**	**20 (1)**	**6 (5)**	**0 (0)**	**0 (0)**	**27 (27)**	**1 (0)**

?* - Dates missing or inconsistent

Table 7: Summary of Deaths Identified by ISD Linkage and/or Reported in HES

Closed Procedures in Children Aged over 365 Days

The table entries are : ***Number of deaths (Number not recorded in HES)***

			Deaths within 30 days of Procedure			**Deaths beyond 30 days of Procedure**		
Inquiry Number	**Unit**	**Total Deaths**	**In-Hospital**	**Post-Discharge**	**?***	**In-Hospital**	**Post-Discharge**	**?***
1	Bristol	6 (6)	0 (0)	0 (0)	0 (0)	0 (0)	6 (6)	0 (0)
2	Leicester	1 (1)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)
3	Leeds	4 (4)	0 (0)	1 (1)	0 (0)	0 (0)	3 (3)	0 (0)
4	Oxford	3 (1)	2 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)
5	Guys	1 (0)	1 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
6	Liverpool	4 (3)	0 (0)	0 (0)	0 (0)	1 (0)	3 (3)	0 (0)
7	Southampton	2 (1)	1 (0)	0 (0)	0 (0)	0 (0)	1 (1)	0 (0)
8	GOS	5 (5)	0 (0)	0 (0)	0 (0)	0 (0)	5 (5)	0 (0)
9	Newcastle	5 (2)	3 (0)	0 (0)	0 (0)	0 (0)	2 (2)	0 (0)
10	Harefield	7 (2)	5 (0)	0 (0)	0 (0)	0 (0)	2 (2)	0 (0)
11	Birmingham	9 (6)	3 (0)	1 (1)	0 (0)	0 (0)	5 (5)	0 (0)
12	Brompton	5 (5)	0 (0)	0 (0)	0 (0)	0 (0)	5 (5)	0 (0)
	Elsewhere	10 (3)	6 (0)	0 (0)	0 (0)	1 (0)	3 (3)	0 (0)
	Total	**62 (39)**	**21 (0)**	**2 (2)**	**0 (0)**	**2 (0)**	**37 (37)**	**0 (0)**

?* - Dates missing or inconsistent

Table 8: Summary of Deaths Identified by ISD Linkage and/or Reported in HES

Open Procedures in Children Aged 0 to 90 Days

The table entries are : ***Number of deaths (Number not recorded in HES)***

			Deaths within 30 days of Procedure			**Deaths beyond 30 days of Procedure**		
Inquiry Number	**Unit**	**Total Deaths**	**In-Hospital**	**Post-Discharge**	**?***	**In-Hospital**	**Post-Discharge**	**?***
1	Bristol	25 (3)	19 (0)	2 (0)	3 (2)	0 (0)	0 (0)	1 (1)
2	Leicester	20 (4)	16 (0)	0 (0)	0 (0)	0 (0)	4 (4)	0 (0)
3	Leeds	31 (12)	18 (0)	3 (3)	0 (0)	1 (0)	9 (9)	0 (0)
4	Oxford	23 (4)	19 (2)	0 (0)	0 (0)	2 (0)	2 (2)	0 (0)
5	Guys	24 (0)	17 (0)	0 (0)	2 (0)	4 (0)	1 (0)	0 (0)
6	Liverpool	42 (8)	31 (1)	1 (1)	0 (0)	4 (0)	6 (6)	0 (0)
7	Southampton	21 (4)	15 (0)	0 (0)	0 (0)	1 (0)	5 (4)	0 (0)
8	GOS	46 (8)	32 (0)	3 (1)	3 (2)	3 (0)	3 (3)	2 (2)
9	Newcastle	25 (4)	20 (0)	0 (0)	0 (0)	1 (0)	4 (4)	0 (0)
10	Harefield	20 (3)	13 (0)	1 (0)	0 (0)	3 (0)	3 (3)	0 (0)
11	Birmingham	59 (9)	42 (1)	1 (0)	3 (0)	5 (0)	8 (8)	0 (0)
12	Brompton	30 (5)	23 (0)	2 (1)	0 (0)	1 (0)	4 (4)	0 (0)
	Elsewhere	4 (2)	1 (0)	0 (0)	0 (0)	1 (0)	2 (2)	0 (0)
	Total	**370 (66)**	**266 (4)**	**13 (6)**	**11 (4)**	**26 (0)**	**51 (49)**	**3 (3)**

?* - Dates missing or inconsistent

Table 9: Summary of Deaths Identified by ISD Linkage and/or Reported in HES

Open Procedures in Children Aged 91 to 365 Days

The table entries are : ***Number of deaths (Number not recorded in HES)***

			Deaths within 30 days of Procedure			**Deaths beyond 30 days of Procedure**		
Inquiry Number	**Unit**	**Total Deaths**	**In-Hospital**	**Post-Discharge**	**?***	**In-Hospital**	**Post-Discharge**	**?***
1	Bristol	26 (6)	18 (0)	0 (0)	1 (0)	1 (0)	4 (4)	2 (2)
2	Leicester	9 (0)	9 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
3	Leeds	13 (5)	6 (0)	0 (0)	0 (0)	2 (0)	5 (5)	0 (0)
4	Oxford	7 (1)	5 (0)	0 (0)	0 (0)	1 (0)	1 (1)	0 (0)
5	Guys	7 (1)	5 (0)	0 (0)	0 (0)	1 (0)	1 (1)	0 (0)
6	Liverpool	24 (12)	11 (0)	0 (0)	0 (0)	1 (0)	12 (12)	0 (0)
7	Southampton	9 (4)	5 (0)	0 (0)	0 (0)	0 (0)	4 (4)	0 (0)
8	GOS	31 (13)	16 (0)	0 (0)	5 (4)	1 (0)	9 (9)	0 (0)
9	Newcastle	10 (3)	5 (0)	0 (0)	0 (0)	2 (0)	3 (3)	0 (0)
10	Harefield	20 (7)	11 (0)	2 (2)	0 (0)	2 (0)	5 (5)	0 (0)
11	Birmingham	20 (8)	10 (0)	1 (1)	0 (0)	2 (0)	7 (7)	0 (0)
12	Brompton	12 (5)	7 (0)	0 (0)	0 (0)	0 (0)	5 (5)	0 (0)
	Elsewhere	3 (3)	0 (0)	0 (0)	0 (0)	0 (0)	3 (3)	0 (0)
	Total	**191 (68)**	**108 (0)**	**3 (3)**	**6 (4)**	**13 (0)**	**59 (59)**	**2 (2)**

?* - Dates missing or inconsistent

Table 10: Summary of Deaths Identified by ISD Linkage and/or Reported in HES

Open Procedures in Children Aged over 365 Days

The table entries are : ***Number of deaths (Number not recorded in HES)***

			Deaths within 30 days of Procedure			**Deaths beyond 30 days of Procedure**		
Inquiry Number	**Unit**	**Total Deaths**	**In-Hospital**	**Post-Discharge**	**?***	**In-Hospital**	**Post-Discharge**	**?***
1	Bristol	27 (4)	17 (0)	2 (0)	2 (0)	2 (0)	4 (4)	0 (0)
2	Leicester	9 (4)	5 (0)	1 (1)	0 (0)	0 (0)	3 (3)	0 (0)
3	Leeds	30 (8)	18 (0)	2 (1)	1 (0)	2 (0)	7 (7)	0 (0)
4	Oxford	13 (6)	5 (0)	0 (0)	1 (0)	1 (0)	6 (6)	0 (0)
5	Guys	15 (5)	10 (0)	2 (2)	0 (0)	0 (0)	3 (3)	0 (0)
6	Liverpool	39 (12)	25 (0)	2 (1)	1 (0)	0 (0)	11 (11)	0 (0)
7	Southampton	12 (5)	6 (0)	0 (0)	0 (0)	1 (0)	5 (5)	0 (0)
8	GOS	50 (14)	32 (0)	2 (2)	1 (1)	4 (0)	10 (10)	1 (1)
9	Newcastle	17 (3)	13 (0)	0 (0)	1 (0)	0 (0)	3 (3)	0 (0)
10	Harefield	38 (3)	33 (0)	2 (0)	0 (0)	0 (0)	3 (3)	0 (0)
11	Birmingham	22 (8)	14 (0)	0 (0)	0 (0)	0 (0)	8 (8)	0 (0)
12	Brompton	37 (9)	24 (0)	2 (1)	0 (0)	3 (0)	8 (8)	0 (0)
	Elsewhere	3 (2)	1 (0)	0 (0)	0 (0)	0 (0)	2 (2)	0 (0)
	Total	**312 (83)**	**203 (0)**	**15 (8)**	**7 (1)**	**13 (0)**	**73 (73)**	**1 (1)**

?* - Dates missing or inconsistent

Table 11: Deaths Identified by ISD Linkage within 30 days of Procedure but NOT Captured by HES

		All Cases		Open Procedures in Children Aged under One Year	
Inquiry Number	**Unit**	**'Missed' Deaths***	**Percent**	**'Missed' Deaths***	**Percent**
1	Bristol	3/74	4%	2/43	5%
2	Leicester	3/41	7%	0/25	0%
3	Leeds	13/67	19%	3/27	11%
4	Oxford	6/40	15%	2/24	8%
5	Guys	2/42	5%	0/24	0%
6	Liverpool	3/91	3%	2/43	5%
7	Southampton	1/32	3%	0/20	0%
8	GOS	12/108	11%	7/59	12%
9	Newcastle	6/54	11%	0/25	0%
10	Harefield	2/73	3%	2/27	7%
11	Birmingham	8/91	9%	2/57	4%
12	Brompton	8/72	11%	1/32	3%
	Elsewhere	1/21	5%	0/1	0%
	Total	**68/806**	**8.4%**	**21/407**	**5.2%**

* 'Missed' in inverted commas since HES is not designed to capture 30-day mortality

Table 12: Comparison of UKCSR deaths with linked HES / ONS deaths

Inquiry Number	Unit	Year 1992		1993/94		1994/95	
		HES/ONS	UKCSR	HES/ONS	UKCSR	HES/ONS	UKCSR
1	Bristol	16	12	20	20	17	17
2	Leicester	12	15	10	9	8	12
3	Leeds	21	12	17	?	9	?
4	Oxford	13	12	12	8	8	0
5	Guys	12	18	5	9	5	15
6	Liverpool	21	22	32	35	17	12
7	Southampton	11	18	6	7	6	8
8	GOSH	35	44	27	?	11	?
9	Newcastle	10	8	9	6	17	15
10	Harefield	13	22	18	18	18	22
11	Birmingham	27	36	26	17	21	29
12	Brompton	17	26	12	8	21	13

Shading indicates instances where the UKCSR data under-report deaths relative to the HES/ONS lower bound.